

ORIGINAL PAPER

WHAT IT MEANS FOR PEOPLE TO BE MECHANICALLY VENTILATED VIA A TRACHEOSTOMY AT HOME: A QUALITATIVE STUDY

Veronika Nelissen, Sabine Metzging, Wilfried Schnepf

Department of Nursing Science, Faculty of Health, University of Witten/Herdecke, Germany

Received November 25, 2018; Accepted July 28, 2019. Copyright: This is an open access article distributed under the terms of the Creative Commons Attribution International License (CC BY). <http://creativecommons.org/licenses/by/4.0/>

Abstract

Aim: Some patients with an acute or chronic disease need home mechanical ventilation via a tracheostomy (invasive HMV). Little is known about the experiences of those affected. This study examined the experiences and life circumstances of people in Germany with invasive HMV. **Design:** A qualitative research design was selected. **Methods:** Problem-centered interviews were held with 20 patients who received invasive HMV. Grounded Theory method and methodology were used. **Results:** The affected people realize that they need invasive HMV and that this will allow them to continue to live. They want to be seen as human beings and to be able to trust the nursing staff. However, they need information and to be able to communicate, thereby regaining their independence and leading a self-determined life. **Conclusion:** The participants just want to live their life despite invasive HMV. The knowledge and experience of nurses can inspire trust and give those affected the necessary sense of safety.

Keywords: chronic illness, communication, information, intensive care, mechanical ventilation, qualitative research, trust.

Introduction

Developments in intensive care and invasive home mechanical ventilation (HMV) mean that an increasing number of people are surviving life-threatening diseases and are being cared for outside intensive care units (ICUs). An alternative to invasive HMV is the use of a nose or face mask (non-invasive), but as this is not always sufficient, invasive HMV via a tracheostomy with a tracheal tube can become essential. Only this form of ventilation allows sufferers to continue to live, especially outside hospital.

In Germany, invasive HMV patients can be cared for in various environments outside hospital: in their own homes, in assisted living facilities, in intensive care residential communities, and in specialized inpatient care facilities. The care of invasively ventilated patients in Germany is a labor-intensive and, therefore, expensive service [Deutsche Interdisziplinäre Gesellschaft für Außerklinische Beatmung (DIGAB e.V.) et al., 2017].

A review of the international literature on invasively and non-invasively mechanically ventilated patients (Nelissen, Metzging, Schnepf, 2018) revealed the

difficulties that patients associated with mechanical ventilation. It indicated that the participants found it difficult to make an informed choice in favor of invasive HMV (Dreyer, Steffensen, Pedersen, 2010a). In particular, they would have liked to have more decision-making support (Lindahl, Sandman Rasmussen, 2005; Dreyer, Steffensen, Pedersen, 2010a). It was important for them to receive comprehensive information about life with HMV, tailored to their needs (van Kesteren, Velthuis, van Leyden, 2001; Ballangrud, Bogsti, Johansson, 2009; Lindahl, 2010; Dyrstad, Hansen, Gundersen, 2013). The initial lack of communication was described as traumatic (Brooks et al., 2004; Laakso et al., 2011). If support from qualified medical staff was lacking, a long, lonely battle had to be fought to regain the ability to speak (Laakso et al., 2011). Being able to communicate, on the other hand, contributes to a feeling of security (Ewers, Schaepe, Lehmann, 2017; Schaepe, Ewers, 2017), and ventilated patients described a successful collaboration as one that ensured they were included in making decisions regarding future life, treatment and support (Brooks et al., 2004; Lindahl, 2010; Dyrstad, Hansen, Gundersen, 2013).

The review also revealed how patients who had experienced both non-invasive and invasive ventilation preferred invasive HMV (Dreyer, Steffensen, Pedersen, 2010a). People who were

Corresponding author: Veronika Nelissen, Department of Nursing Science, Faculty of Health, University of Witten/Herdecke, Stockumer Strasse 12, Witten, Germany; e-mail: Veronika.Nelissen@uni-wh.de

mechanically ventilated wanted to lead as normal a life as possible without it being dominated by the ventilation. Leisure time activities, and family and friends continue to be important in life, contributing to a feeling of contentment (Brooks et al., 2004; Ballangrud, Bogsti, Johansson, 2009; Dreyer, Steffensen, Pedersen, 2010b). The participants also reported that trusting and having confidence in the competence of their own support staff was the basis for a feeling of security when being cared for at home (van Kesteren, Velthuis, van Leyden, 2001; Ballangrud, Bogsti, Johansson, 2009; Lindahl, 2010; Dyrstad, Hansen, Gundersen, 2013; Schaepe, Ewers, 2017). Endotracheal suctioning is described as a special situation of trust (van Kesteren, Velthuis, van Leyden, 2001; Brooks et al., 2004; Dreyer, Steffensen, Pedersen, 2010a).

However, both in Germany and internationally, there is a lack of data concerning outpatients receiving invasive HMV. This field is relatively unexplored.

Aim

This study examined the experiences and life circumstances of people with HMV via a tracheostomy (invasive HMV). The research question was: “What are the experiences of people with invasive HMV and how do they cope with them?”

Methods

Design

Experiences of invasive HMV as perceived by the chronically ill were investigated, thus reconstructing experiences from the perspective of those concerned. To generate this point of view as accurately as possible from the data, a qualitative research approach was chosen, using the Grounded Theory method and methodology (Glaser, Strauss, 1967; Strauss, Corbin, 1990). This research method, and an open and explorative approach are chosen to identify and understand phenomena that are little known or to expand existing knowledge (Strauss, Corbin, 1996).

Sample

This study focuses exclusively on 20 invasively ventilated people – seven female and 13 male – who were at least 18 years old when invasive HMV began. Ventilation could be intermittent or continuous. The participants had to be responsive and oriented, and communication had to be possible, either verbally or in some other way. The intention was to interview invasively ventilated people with differing diagnoses in various residential arrangements. All requirements were met.

The youngest participant was 19 years old when invasive HMV commenced, while the oldest was 86. Average age at the start of invasive HMV was 60 years. The participants had been ventilated over periods of between two months and 24 years when the interviews were held.

The interviews lasted between 00:21:47 and 03:10:40 hours, with an average of 01:04:18 hours per interview. Interviews with seven of the participants were conducted during a ventilation-free period. Another six were able to speak during invasive HMV. Seven participants wrote their answers down, were lip-read, or used a language PC. Participants were alone in nine of the interviews; while a member of the family and/or care service was present for interviews with 11 participants. The people present were supportive, and the nurses had a special relationship with the participants, with one exception. Table 1 provides further information about the characteristics of each participant.

Data collection

Problem-centered interviews (Witzel, 2000) were conducted between January 2015 and May 2016, using an interview guide. The guide was developed from the research question, the known literature on this topic and the expert knowledge of the interviewer. Focused questions such as general and specific soundings, or ad hoc questions complemented the interview guide. Since the analysis of the interviews was an on-going process, questions arising during the analysis were also included in the problem-oriented interview.

Participants were approached through a “gatekeeper” who had developed a relationship with potential participants. This gatekeeper could be a nurse, a doctor or a provider. The initial written information was passed on to the potential participant via the gatekeeper and a date for the interview was agreed on with the participant. Social data were collected in advance by means of a short questionnaire. Just before the interview, the participants received further information telling them that they could break off the interview at any time and withdraw their consent, and also that the data collected would be anonymized. The participants gave their written consent to the interview. All interviews were conducted by the same researcher. The interviewer has worked in healthcare for many years and is experienced in caring for invasively ventilated people. Any existing problems and starting difficulties experienced with invasive HMV and in outpatient care could only be assumed. This study was therefore conducted to provide more reliable data on these assumptions.

The first codings and analyses were performed simultaneously with data collection in order to make theoretically justified decisions for further data collection (Glaser, Strauss, 1967). Theoretical sampling helps to answer questions arising from the analysis and to close any gaps. The questions asked included: “How did participants find the start of invasive mechanical ventilation?”; “How can participants tell whether carers are capable of meeting the demands for the care of ventilated people?” A memo made at each interview described the interview situation and the observations made. Data collection was concluded when data saturation was reached.

Data analysis

The interviews were recorded digitally, transcribed word for word by the interviewer, and analyzed using the MAXQDA11 software (VERBI Software GmbH). To add to the rigor of the analysis, excerpts from the interviews were analyzed and discussed by a team consisting of the authors and researchers in midwifery and nursing science. The analysis of the interviews began with the first transcription in the form of open coding, while simultaneously examining primary phenomena. The primary phenomena were examined with regard to their common features, similarities, differences, and dimensions. These were either confirmed during the following interviews, or more were added. Repeated phenomena thus had a confirmed theoretical relevance (Strauss, Corbin, 1990). This continuous review process was maintained from interview to interview, in an iterative-cyclical process.

Axial coding followed open coding. With the help of coding paradigms (Strauss, Corbin, 1990), the phenomena were put in relationship to each other. Here the causal conditions for a phenomenon were named, and the context and intervening conditions were described. Furthermore, the behavior patterns and strategies that the participants developed, and the consequences they drew were revealed. The analysis was accompanied by written memos. Open and axial coding was followed by selective coding. Despite all difficulties, “wanting to live on” was identified as a central phenomenon. This phenomenon was correlated with the other relevant categories, thus reconstructing the perspective of the participants (Strauss, Corbin, 1990). This perspective includes interactions between carers, relatives and friends, healthcare institutions, and participants’ “relationship” with the technology (Blumer, 1969). From the entire study, this article presents five aspects of life with invasive HMV, those which make

it more difficult to go on living, and those without which it would be impossible to go on living at all.

Results

Few participants had realized that their existing progressive illness would lead to invasive HMV. Despite having a neurodegenerative disease and experiencing deterioration in respiration, or already being on mask ventilation, patients had no counseling or informative discussions with medical personnel about impending invasive ventilation. Even when repeated hospital admissions were required due to the persistent deterioration of a chronic lung disease, the participants received no corresponding information: *“Recently, everything went downhill so quickly that I had to be put into a coma and ventilated all the time. I only realized this for the first time in hospital; I hadn’t even realised that there was such a thing. I thought, ‘what’s going to happen now?’ I thought I would have to stay on the ICU forever.”* The lack of information meant that participants could not deal with or prepare themselves for the coming tracheostomy and invasive HMV. They did not know what to expect, and could not imagine being able to live outside hospital.

Before receiving invasive HMV, although many of the participants experienced poor sleep, were tired during the day, and felt sleepy and weak, they failed to make a connection to their restricted breathing capacity. The decline in performance increased gradually over an extended period of time. Strictly speaking, they did not feel ill. Only with the start of invasive HMV, following a dramatic turn in the course of the illness, did they notice a difference. The participants felt better, slept better, and had more strength and energy during the day: *“Well, before I was always tired and weak, really just not fit enough. But now I’ve got the ventilator, I’ve noticed I feel fitter and have more energy.”*

Since finding that invasive HMV brings overall benefits, and greater quality of life, the participants are prepared to accept major restrictions. Invasive HMV is seen as life-saving and “a help”. Participants with intermittent mechanical ventilation, while being glad of the time they have without mechanical ventilation, particularly since they are then able to speak and eat well, nevertheless, also appreciate the time when using the ventilator. Participants consider the ventilation-free periods as hard labor and know well that life without invasive HMV is not possible for them, as the following quote indicates: *“After about one, two hours I tell them to put me back on ventilation. I can’t carry on. It’s just too difficult. You get tired and weak.”* As a result, the participants

Table 1 Characteristics of participants

No.	Primary Diagnosis	Age (years)	Age at start of ventilation	HMV* experience (years)	Gender	Hours /day with HMV	Form of Living	Living circumstances at home
1	Motor Neuron Disease	85	79	5	m	24	at home	with life companions
2	Chronic obstructive pulmonary disease	51	47	4	w	24	intensive care	
3	Motor Neuron Disease	75	73	2	m	24	residential community intensive care	
4	Motor Neuron Disease	64	61	3	m	24	residential community at home	with spouse
5	Cardiac decompensation	80	77	2	m	< 12	assisted living facility	alone
6	Chronic obstructive pulmonary disease	90	86	4	m	24	intensive care	
7	Chronic obstructive pulmonary disease	66	62	4	m	24	residential community intensive care	
8	Congenital myopathy of unclear genesis	48	24	24	w	24	residential community at home	alone
9	Mucopolysaccharidosis type VI	29	26	3	w	< 12	at home	with parents
10	Morbid obesity	62	62	0,3	m	< 18	specialized inpatient care facility	
11	Chronic obstructive pulmonary disease	85	85	0,2	m	24	specialized inpatient care facility	
12	Chronic obstructive pulmonary disease	58	57	1,2	w	< 18	intensive care	
13	Chronic obstructive pulmonary disease	59	58	0,3	m	< 12	residential community specialized inpatient care facility	
14	Progressive muscular dystrophy	63	61	2,5	w	24	intensive care	
15	Phrenic nerve palsy with diaphragmatic elevation	81	73	8	w	24	residential community assisted living facility	alone
16	Chronic obstructive pulmonary disease	63	58	5	m	24	intensive care	
17	Motor Neuron Disease	74	73	1	m	< 18	residential community at home	with spouse
18	Incomplete cross-section paralysis	60	58	2,5	w	< 18	at home	alone
19	Complete cross-section paralysis	23	19	4	m	24	at home	with parents
20	Chronic obstructive pulmonary disease	70	67	3,5	m	24	specialized inpatient care facility	

*HMV – Home Mechanical Ventilation

become accustomed to invasive HMV and the associated restrictions over time: “You have to get used to it, it’s a matter of habit.” The ventilator becomes part of them, like other auxiliary devices. Overall, the participants are glad to have invasive HMV, since they can breathe again and are able to get on with their lives.

To be seen as a human being

However, not every experience boosts the participants’ desire to continue living. At the beginning of invasive HMV, a period of critical illness, the participants complain of not being treated as human. This feeling is intensified through the loss of voice and the inability to speak, due to the tracheostomy: “They talked as if I weren’t there at all. As if I were deaf, or not quite right in the head ...

that sort of thing, a bad situation. It was ... degrading. On the other hand, what can you do?” The participants are no longer regarded as human beings; they are overlooked, and feel stigmatized. Physicians and nurses stand at their beds talking over them. Those affected are unable to express themselves verbally or to draw attention to themselves, and cannot, therefore, ask the questions that could provide them with answers about their present situation. They feel at the mercy of strangers, and as if they were mere objects. The patients are not told anything; they receive no information about their condition. They do not know what the tube in their throat is for or why they cannot breathe on their own. Without a voice, the participants cannot draw attention to themselves and are invisible. This helplessness leads to resignation and frustration. To

be seen as a human being, patients need to be able to speak or communicate in some way. Nurses and relatives can counterbalance the physical restrictions but not the inability to speak. This ability is considered more important than, for example, mobility. The ability to speak means you can defend yourself: *“And I couldn’t even put up a fight because I couldn’t speak.”* Unable to speak, the participants have to accept whatever the medical staff or their relatives give or do not give them, and put up with how they are treated by their carers. They struggle not so much with being unable to do anything for themselves, but with having no influence over how anything is carried out. They want to decide for themselves how an action is performed. Since non-verbal communication is often not sufficient, they need a voice.

The desire to trust in nurses

One condition for being able to live with ventilation outside a hospital is confidence and trust in the nursing staff. The participants would like to be able to trust that the nurses are qualified in caring for ventilated patients and know what needs to be done; all the more so in outpatient care. While they do not question nurses’ competence in general, who, after all, *“are there to help,”* some participants are critical and enquire about the treatment they receive. They assume that not every care service can fall back on care personnel with knowledge and experience of artificial ventilation, experience which includes knowing how to enable a ventilated person to speak: *“... they were supposed to have experience with HMV ... but weren’t directly prepared for it.”*

The participants are able to recognize whether the nurses are experienced. They try to get to know the carers and to evaluate their skills, since they are living with an invasive HMV device that they cannot manage by themselves and are dependent on support from nurses. Feelings of safety depend on patients being able to build up trust in the nurses. In their own homes, this possibility is denied them by the fact that they have to adjust to new nursing staff time and again, due to high turnover. Since only one nurse is present at any time, and this particular nurse must be trusted, turnover has a negative effect on confidence-building and feelings of security. For some participants, this lack leads to a fear of loss. They report that they almost always have a nurse in their team with whom they have developed a special trust relationship. They are afraid that this trustworthy person will be *“taken away”* from them.

For the participants, getting to know a new nurse means starting over again: telling their medical history, introducing habits and preferences, and also

familiarizing the nurse with the situation. One participant described his view of getting to know the nursing staff in this way: *“I am ... here naked, both physically and emotionally, and there is someone there who makes me feel clothed ... I have confidence, and it is bad when I feel naked again.”* The participant feels unprotected when the trusted nurse is not present. For mechanically ventilated patients who need to be lip-read, for instance, the process of getting to know someone is made more difficult due to communication problems. The new carer must first learn to lip-read, which also requires experience. For this, too, trust is necessary. Trust has to be built up again and again. Each new nurse has to earn this trust; it cannot be built up in advance. The limited private sphere and the feeling of never being alone again make trust in the nursing staff, and the stability of care at home indispensable factors. Endotracheal suctioning and the changing of tracheal cannula represent special trust situations. Here, the ventilated patients form opinions about which nurses are experienced and which nurses they can feel safe with: *“Experience – that is what makes good carers.”* Safety is not a question of good ventilation equipment but of trust in the nurse. The ventilator simply works; should there be problems, the nurse must be able to correct them or connect a replacement ventilator.

To live autonomously again and to regain independence

When they regain their voices, the participants also regain their self-determination. They can communicate and express wishes. It is important for the participants to be able to decide about their daily routine, which includes, for instance, when enteral nutrition should start in the morning, or when body care should take place: *“I had expected to feel better. But it was just the opposite. I was laid down, now and then washed and combed. At six in the morning someone came and just started ... did all sorts of things that I didn’t want.”* This quotation reflects the lack of self-determination patients are granted, and also how care staff treat the participants. Patients with a progressive disease, who have made a conscious decision for invasive HMV, have certain expectations, and hope that the invasive HMV will improve their quality of life. The participants are aware that they will need more help, but they assume that they will continue to determine their own lives. The wishes and needs of the ventilated patients are not always adequately heeded, and so they are also concerned about the qualifications of the nursing staff in this context: *“... sure, I certainly was angry,*

having to depend on this care provider. As I see it, the people were poorly trained."

Patients are existentially dependent on the nursing staff. However, participants may perceive the nursing staff to be poorly trained, not least because they do not know how to behave towards people in need of help. The greater the physical handicap, the more the participants have to fight for themselves. They need advocates who speak up for them, usually members of their family. Those who stand up for themselves in a self-determined manner also regain some of their independence. This independence is ultimately based on help from relatives or nurses. With their support, patients can use a computer, which is seen as *"a window to the world,"* through which participants can get information, contact authorities, institutions, and other people, and then maintain such contacts. The participants actively take part in life again.

Seeing HMV as both an aid and an obstacle

If the interviewees can reshape and influence their lives with more self-determination and independence, the more likely it is they will come to terms with their current life circumstances. They want life to continue to live as normally as possible under the given circumstances. They do not want invasive HMV to dominate their life. It should be part of life without being the center of it; the *person* is more discernible. Life should not be controlled by the invasive HMV technology. Those interviewees suffering from a chronic lung disease have reached a stabilized level of the illness, and since they are feeling somewhat better than before invasive HMV was started, they would like to do more things. However, these activities are prevented due to the absence of a carer in the respective type of accommodation, and also by the invasive HMV equipment itself, which makes the patients immobile. A spontaneous outing, even if it is only a shopping trip, is not possible: *"Well, yes ... I can hardly imagine what it would be like without it, due to the relief. But I'd be glad if I didn't need it."*

The interviewees have adjusted to living with invasive HMV and they feel good; they can hardly imagine living without it. Naturally, they would prefer a life without invasive HMV; they would like to be more independent and not have to rely on assistance from other people. Nevertheless, they have been able to get used to the situation and have regained strength and energy and the associated quality of life. The progressive, life-limiting course of the illness makes life without invasive HMV seem unrealistic. The interviewees are happy about every day they feel well: *"I see and experience each day the way it is and that's good..."* The more hopeless the situation seems, the fewer demands the

interviewees make. For the most part, they are happy to be able to continue to participate in life despite the life-limiting disease. This does not mean that they are content with everything, but they are alive – and that is the crucial factor. One interviewee said: *"I am glad they exist"*, and another stated: *"I can't remember everything, of course. There's a whole lot missing. But as far as I can tell, all is well again."* For this participant *"All is well again"* because he establishes other priorities. For the participants, life settles down to a stable level, sometimes better, sometimes worse than life before invasive HMV. In their present situation, the participants do not give up hope. Although not everything is optimal, they have been able to adjust their life accordingly and are trying to accept it the way it is. The illness and the invasive HMV have overturned their previous plans, and now they have to embrace their new life. Invasive HMV gives the interviewees a new perspective on the disease itself as well as on life.

Discussion

The results show the inner perspective of invasively ventilated people, as well as their individual coping methods (Schaeffer, Moers, 2008). The desire to live is the central phenomenon. The participants want to continue living despite their dependency on technology. According to Corbin (2003), people suffering from a chronic illness do not perceive it as such and learn to live with it and adjust to their disabilities. Although chronic illness was not the focus of the survey, invasive HMV is nevertheless the result of such illness, and the affected people remain dependent on a ventilator. At the onset of invasive HMV, the progressive nature of the chronic illness is interrupted for a short while. Participants receive invasive HMV at a time when, without it, death would be the consequence. Invasive HMV brings the participants respite, and they are able to continue to live for months, years or even decades. The results also show, however, that the underlying conditions at the beginning of invasive ventilation and for life with invasive HMV are not always favorable.

In contrast to non-invasively ventilated patients, invasive HMV patients are always dependent on help from others, usually well-qualified nurses. For all participants, the course of the disease was so advanced that independent handling of the invasive HMV was no longer possible. And yet they all spoke out in favor of continuing life with invasive HMV. The psychological immune system (Menning, 2015) supports this progressive course and helps them to accept the illness and a life that is dependent on

technology. Menning describes the psychological immune system as a system of strength that can contribute to resilience and regeneration. Over time, the familiarization effects become apparent in relation to the disease and to the technological and personnel dependencies. Restrictions that appear unacceptable in full health can be tolerated despite the further progression of the illness. Furthermore, if people wish to continue living, they have no other choice: either they live with invasive HMV or they die (van Kesteren, Velthuis, van Leyden, 2001; Dreyer, Steffensen, Pedersen, 2010a).

Nevertheless, a lack of information at the beginning made it impossible for the participants to prepare themselves for invasive HMV. To be told beforehand about being unable to speak is extremely important (Schaepe, Ewers, 2017). However, participants remained uninformed even after starting invasive HMV. The ventilator and the technology dominate the treatment, while the human being attached is often overlooked and becomes a mere object (Schaeffer, 2004). As early as 1984, Hannich (1984) mentioned that ventilated patients on an ICU wanted information. The lack of information considerably complicates the situation. Despite this, the problem still persists (Wang et al., 2009; Laakso et al., 2011). In an observational study on an ICU, Happ et al. (2011) found that there was a relatively low frequency of communication between nurses and non-speaking patients, and that the exchanges were only brief. They point out that nurses usually initiate communication, and, therefore, have a responsibility both to include patients in communication and to understand them. In their study, Flinterud and Andershed (2015) show that the importance of communication, in particular for people being mechanically ventilated, has been recognized and that humane treatment is possible even on ICUs.

Patients using invasive HMV realize that their capabilities improve when using the ventilator, and that life continues (Brooks et al., 2004; Lindahl, Sandman Rasmussen, 2005; Ballangrud, Bogsti, Johansson, 2009). Normal life is restored through using invasive HMV technology (Schaeffer, Moers, 2008). Many of the participants do not think of themselves as being ill (Antonovsky, 1987; Ballangrud, Bogsti, Johansson, 2009). Invasive HMV has allowed patients to cope with and manage their illness (Antonovsky, 1987; Schaeffer, Moers, 2008). Subsequently, participants have sufficient resources available to cope with living with invasive HMV (Antonovsky, 1987; Menning, 2015).

Being able to speak and to have a voice are seen as essential. In addition, having trust in the nurses and

continuity in care are basic requirements for surviving with invasive HMV (van Kesteren, Velthuis, van Leyden, 2001; Lindahl, Sandman, Rasmussen, 2003; Lindahl, 2010; Dyrstad, Hansen, Gundersen, 2013; Schaepe, Ewers, 2017; Gödecke, 2018). However, nurses must first earn such trust by proving they have the necessary knowledge and experience, which the participants can easily recognize, for instance, when the tracheal tube has to be changed, or during the suction process – procedures which require particular attention and sensitive handling (Donnelly, Wiechula, 2006; Jerusel, 2017). To this day, however, it is clear that the professional demands placed on nursing staff can barely be met (Ewers, Schaepe, Lehmann, 2017; Limberger, Schnepf, 2017). Competent nurses are indispensable for outpatient care (Ballangrud, Bogsti, Johansson, 2009). Future research could address the competencies required of carers in clinical and non-clinical intensive care settings, and in dealing with invasively ventilated patients.

Limitation of study

Since the participants were always contacted via gatekeepers, it is possible that the gatekeepers made a deliberate selection. The overall difficulty of gaining access to the participants made a targeted selection, in the sense of Theoretical Sampling, difficult. A further limitation is that many of the participants wanted either their family or a nurse to be present during the interview; thus the influence of these individuals cannot be ruled out. Participants who could no longer speak were included in this study, which should be seen as strength.

Conclusion

Despite the differences in health systems worldwide, it can be assumed that the individual statements of the people surveyed will be similar and consistent across nationalities. In summary, it can be said for this study that it is important that all those affected should be informed about and prepared for the impending course of the disease. This preparation should comprise information about tracheostomy and HMV, the loss of ability to communicate verbally, and the significant restrictions involved. The study results show that, despite having a variety of problems with invasive HMV, the participants want to continue to have a life when out of hospital.

Ethical aspects and conflict of interest

Due to the vulnerability of the target group, permission was obtained beforehand from the Ethics Commission of the University Witten/Herdecke,

with regard to the revised Helsinki Declaration of the World Medical Association, 1975. Written informed consents were obtained from all participants (Schnell, Heinritz, 2006). The authors declare they have no conflict of interests. This study received no financial support.

Acknowledgments

We would like to thank the participants for sharing their experiences. We also wish to thank the practice partners for their collaboration and help with recruiting participants.

Author contributions

Conception and design (VN, WS); data collection (VN); data analysis and interpretation (VN, SM, WS); manuscript draft (VN); critical revision of the manuscript (VN, SM, WS), final completion of the manuscript (VN, SM).

References

- Antonovsky A. *Unraveling the mystery of health: how people manage stress and stay well*. San Francisco: Jossey-Bass; 1987.
- Ballangrud R, Bogsti WB, Johansson IS. Clients' experiences of living at home with a mechanical ventilator. *Journal of Advanced Nursing*. 2009;65(2):425–434.
- Blumer H. *Symbolic interactionism: perspective and method*. United States: Englewood Cliffs, N. J.; 1969.
- Brooks D, King A, Tonack M, Simson H, Gould M, Goldstein R. User perspectives on issues that influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders. *Canadian Respiratory Journal*. 2004;11(8):547–554.
- Corbin JM. The body in health and illness. *Qualitative Health Research*. 2003;13(2):256–267.
- Deutsche Interdisziplinäre Gesellschaft für Außerklinische Beatmung (DIGAB e.V.), zusammen mit Bund der Pneumologen (BdP); Deutsche Gesellschaft für Neurologische Intensivmedizin (DGNI e.V.); Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin (DGP e.V.); Deutscher Hausärzteverband e.V.; Deutsche Interdisziplinäre Vereinigung für Intensivmedizin (DIVI e.V.); Verband Pneumologischer Kliniken (VPK). Positionspapier zur aufwendigen ambulanten Versorgung tracheotomierter Patienten mit und ohne Beatmung nach Langzeit-Intensivtherapie (sogenannte ambulante Intensivpflege). *Pneumologie*. 2017;71:204–206. (in German)
- Donnelly F, Wiechula R. The lived experience of a tracheostomy tube change: a phenomenological study. *Journal of Clinical Nursing*. 2006;15(9):1115–1122.
- Dreyer PS, Steffensen BF, Pedersen BD. Life with home mechanical ventilation for young men with Duchenne muscular dystrophy. *Journal of Advanced Nursing*. 2010a;66(4):753–762.
- Dreyer PS, Steffensen BF, Pedersen BD. Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation. *International Journal of Qualitative Studies on Health and Well-Being*. 2010b;5. doi: 10.3402/qhw.v5i3.5388.
- Dyrstad DN, Hansen BS, Gundersen EM. Factors that influence user satisfaction: tracheotomised home mechanical ventilation users' experiences. *Journal of Clinical Nursing*. 2013;22(3–4):331–338.
- Ewers M, Schaepe C, Lehmann Y. Alles sicher? – Risikosituationen in der häuslichen Intensivpflege aus Sicht beatmeter Patienten und ihrer Angehörigen. *Pflege*. 2017;30(6):365–373. (in German)
- Flinterud SI, Andershed B. Transitions in the communication experiences of tracheostomised patients in intensive care: a qualitative descriptive study. *Journal of Clinical Nursing*. 2015;24(15–16):2295–2304.
- Glaser BG, Strauss AL. *The discovery of grounded theory – strategies for qualitative research*. New York: Aldine de Gruyter; 1967.
- Gödecke C. *Langzeitbeatmung im eigenen Lebensumfeld. Sichtweisen auf die Pflege in der außerklinischen Beatmung*. Frankfurt am Main: Mabuse-Verlag; 2018. (in German)
- Hannich HJ. Erfassung aktueller Erlebnisinhalte von beatmeten Patienten auf der Intensivstation. *Anästhesiologie Intensivmedizin Notfallmedizin Schmerztherapie*. 1984;19(03):124–128. (in German)
- Happ MB, Garrett K, Thomas DD, Tate J, George E, Houze M, Radtke J, Sereika, S. Nurse-patient communication interactions in the intensive care unit. *American Journal of Critical Care*. 2011;20(2):e28–e40.
- Jerusel R. Das Erleben von Menschen mit Tracheostoma im häuslichen Setting. *Pflegewissenschaft*. 2017;19(9/10):468–474. (in German)
- Laakso K, Markström A, Idvall M, Havstam C, Hartelius L. Communication experience of individuals treated with home mechanical ventilation. *International Journal of Language & Communication Disorders*. 2011;46(6):686–699.
- Limberger R, Schnepf W. Die Heimbeatmungssituation aus Sicht von Angehörigen und Familien. *Kontext*. 2017;48(1):30–44. (in German)
- Lindahl B, Sandman PO, Rasmussen BH. Meanings of living at home on a ventilator. *Nursing Inquiry*. 2003;10(1):19–27.
- Lindahl B, Sandman PO, Rasmussen BH. On becoming dependent on home mechanical ventilation. *Journal of Advanced Nursing*. 2005;49(1):33–42.
- Lindahl, B. Patients' suggestions about how to make life at home easier when dependent on ventilator treatment – a secondary analysis. *Scandinavian Journal of Caring Sciences*. 2010;24(4):684–692.
- Menning H. *Das psychische Immunsystem. Schutzschild der Seele*. Göttingen [u.a.]: Hogrefe; 2015. (in German)
- Nelissen V, Metzing S, Schnepf W. Erfahrungen außerklinisch invasiv und nicht invasiv beatmeter Menschen – eine systematische Literaturrecherche qualitativer Forschungen. *Pneumologie*. 2018;72(7):514–522. (in German)
- Schaeffer D. *Der Patient als Nutzer. Krankheitsbewältigung und Versorgungsnutzung im Verlauf chronischer Krankheit*. Bern: Hans Huber; 2004. (in German)
- Schaeffer D, Moers M. Überlebensstrategien – ein Phasenmodell zum Charakter des Bewältigungshandelns chronisch Erkrankter. *Pflege und Gesellschaft*. 2008;13(1):6–31. (in German)
- Schaepe C, Ewers M. “I need complete trust in nurses” – home mechanical ventilated patients' perceptions of safety.

Scandinavian Journal of Caring Sciences. 2017;31(4):948–956.

Schnell MW, Heinritz C. *Forschungsethik. Ein Grundlagen- und Arbeitsbuch für die Gesundheits- und Pflegewissenschaft*. Bern: Hans Huber; 2006. (in German)

Strauss AL, Corbin JM. *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, Calif [u.a.]: Sage Publications; 1990.

Strauss AL, Corbin JM. *Grounded Theory. Grundlagen qualitativer Sozialforschung*. Weinheim: Beltz, PsychologieVerlagsUnion; 1996. (in German)

van Kesteren RG, Velthuis B, van Leyden LW. Psychosocial problems arising from home ventilation. *American Journal of Physical Medicine & Rehabilitation*. 2001;80(6):439–446.

Wang K, Zhang B, Li C, Wang C. Qualitative analysis of patients' intensive care experience during mechanical ventilation. *Journal of Clinical Nursing*. 2009;18(2):183–190.

Witzel, A. The problem-centered interview. *Forum: Qualitative Social Research*. 2000;1(1). doi.org/10.17169/fqs-1.1.1132.